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## STRATEGIES FOR COPING WITH PAIN PRESENTED BY ADOLESCENTS WITH HEMATOPOIETIC MALIGNANCIES

**Abstract:** *Strategies for coping with pain presented by adolescents with hematopoietic malignancies.*

**Introduction:** Leukaemias and lymphomas are the most common malignant diseases diagnosed among adolescents and they are associated with pain and anxiety. As a result they may affect the way patients accept their disease and determine subjective assessment of quality of life. The objective of this study was to recognise strategies for coping with pain, evaluate the process of accepting the disease and assess quality of life among adolescents diagnosed with hematopoietic malignancies.

**Material and Methods:** The study group comprised 66 patients aged between 14 and 21 and diagnosed with leukaemia or lymphoma. The following measuring tools were used: the Pain Coping Strategies Questionnaire (CSQ), Zung Self-Rating Anxiety Scale (SAS), Acceptance of Illness Scale (AIS), and WHOQOL-BREF for quality of life evaluation.

**Results:** *Coping self-statements* and *praying or hoping* were the two most common strategies used by our respondents when coping with pain. In the study group the level of anxiety had no influence on pain control and the ability to reduce it. A statistically significant relation was found between the level of catastrophizing as a method of coping with pain and quality of life in the physical domain. An additional correlation was observed between quality of life in the psychological domain and the level of pain control.

**Conclusions:** The ability of coping with pain promotes the acceptance of illness and improves patient's quality of life. The age and duration of the disease were factors affecting strategies for coping with pain. A small percentage of respondents who experienced anxiety suggests that further and deeper research is needed in this field.

**Keywords:** adolescents, malignant disease, pain, anxiety, acceptance of disease.

## INTRODUCTION

Adolescence is a very difficult and stormy period of everyone's life. The diagnosis of a life-threatening disease, there is no doubt that cancer belongs to that group, is a disturbance in teenager's life, which is supposed to be rich and dominated by self-esteem and the sense of independence. Basic needs of self-reliance, good image, sexuality and being accepted are directly confronted with illness. An adolescent wants to preserve his/her autonomy and self-determination and these aspirations are threatened by forced dependency and loss of control. The state of serious disease and burden related to its treatment comprise contradictory combination forming teenager's skills and weakening abilities resulting from his/her illness [1, 2].

The problem of coping with the disease becomes a key element in the therapeutic process, especially for young patients. It determines patient's quality of life and his/her functioning among peers, which later is going to be reflected in processes of treatment and recovery. When discussing the issue of adjustment as a process of adaptation, organism's physiology as well as psychological and social dimensions must be taken into consideration. Adjustment, which is a part of psychic adaptation to one's illness, generally aims at restoring psychic balance and managing problems resulting from the disease. However, it is impossible for an adolescent to adjust to numerous situations related to his/her disease, which may seem unimportant, if this young person doesn't understand what causes these situations [2].

Adjustment to the disease is directly associated with quality of life determined by health status (HRQOL). When studying how young patients cope with malignant diseases and evaluate their quality of life, the following problems must be addressed: pain with its type and localisation, anxiety, complications related to treatment (weakness, fatigue, sensitivity, vomiting, abdominal pain), fatigue and functioning of family members [3–5]. Intense emotions experienced by parents may affect adjustment processes and teenager's quality of life [6, 7]. Hinds *et al.* [8] emphasize the importance of studies on quality of life because this may potentially help to create effective communication with patients and improve the level of trust in relations between patients and their physicians as well as patients and their parents. Additionally, it improves patient satisfaction with medical care due to more precise identification of patient's needs. Young people diagnosed with malignant diseases comprise a special group of patients, who should receive greater attention since malignancies in adolescence vary in many aspects from cancers diagnosed among children and adult patients. Also, in this difficult period of life teenage patients experience many problems associated with acceptance and treatment of their diseases as well as adjustment to life after the therapy ends [9]. Therefore, research in this field seems to be relevant in order to obtain information about strategies for coping with pain,

anxiety, the process of accepting the disease, and quality of life of adolescents diagnosed with malignancies based on the example of teenage patients with leukaemia or lymphoma.

## MATERIAL AND METHODS

The study was performed between 2009 and 2012 in the Clinic of Oncology and Haematology and the Clinic of Hematopoietic Stem Cell Transplantation, University Children's Hospital of Cracow, and Oncology Outpatient Clinic and the Clinic of Haematology and Oncology, Specialist Children's Hospital in Lublin.

Our study group included 66 patients aged between 14 and 21 years and hospitalised because of leukaemia ( $n = 57$ ) and lymphoma ( $n = 9$ ) and visiting outpatient oncology clinics. Study eligibility criteria included: the diagnosis of leukaemia or lymphoma, obtained consent for the participation in the study (legal guardian's consent if the patient was younger than 18 years old), undergone chemotherapy (one cycle at least), and no need for continuous administration of analgesic medications (VAS score  $< 5$ ). Patients with coexisting disorders of other systems or organs, those undergoing chemotherapy and experiencing side effects from this type of treatment, those requiring continuous administration of analgesic drugs, and young patients in terminal stage of their disease were excluded from this study.

The following measuring tools were used: The Pain Coping Strategies Questionnaire (CSQ) adapted by Juczyński [10], Zung Self-Rating Anxiety Scale (SAS), Acceptance of Illness Scale (AIS), and WHOQOL-BREF (World Health Organisation Quality of Life) for quality of life evaluation.

Statistical analysis examining relationships between different variables was based on two parametric tests, i.e. Student's t-test and Pearson's correlation test, and two non-parametric ones i.e. Mann-Whitney U-test and Spearman's rank correlation coefficient. The level of significance was 0.05 ( $\alpha = 0.05$ ).

## RESULTS

Girls represented 56.1% ( $n = 37$ ) of all respondents aged between 14 and 21 whereas remaining 43.9% ( $n = 29$ ) were boys. As far as patient's age was concerned 36.4% ( $n = 24$ ) were between 14 and 15, adolescents older than 16 and younger than 17 comprised 31.8% ( $n = 21$ ), 18 to 19 year old subgroup included 24.3% ( $n = 16$ ) of all participants whereas 7.5% ( $n = 5$ ) of patients were between 20 and 21 years old. The mean age was 16.5 (SD = 2.0 years).

More than 54.5% of our respondents had been ill for more than 2 years and remaining 45.5% of the group had suffered from their diseases for a period shorter than 2 years.

Patients with acute lymphoblastic leukaemia (ALL) comprised the most numerous subgroup (77.3%,  $n = 51$ ). Acute myeloid leukaemia (AML) was diagnosed in 9.1% ( $n = 6$ ) of our respondents, Non-Hodgkin lymphoma (NHL) and Hodgkin's disease (HD) were reported in 7.5% ( $n = 5$ ) and 6.1% ( $n = 4$ ) patients, respectively.

### Coping skills and pain management skills — the Pain Coping Strategies Questionnaire

Two strategies i.e.: "*coping self-statements*" ( $\bar{x} = 19.76$ ;  $SD = 7.42$ ; NS) and "*praying and hoping*" ( $\bar{x} = 19.24$ ;  $SD = 8.82$ ; NS), were declared by respondents most frequently. "*Reinterpreting pain sensations*" was the least common coping strategy ( $\bar{x} = 8.79$ ;  $SD = 6.42$ ; NS).

Patients assessed their skills for pain control as average ( $\bar{x} = 3.1$ ;  $SD = 1.2$ ;  $p < 0.05$ ) similarly as their ability to reduce it ( $\bar{x} = 2.83$ ;  $SD = 1.1$ ;  $p < 0.001$ ). The biggest number of adolescents (37.9%,  $n = 25$ ) declared partial control over their pain. Two respondents (3%) had no control over pain whereas 3% ( $n = 2$ ) managed it completely.

As far as the ability to reduce pain sensations was concern, 50% ( $n = 33$ ) of our respondents were able to relive their pain partially, however none of them achieved total pain reduction. Three patients (4.5%) were unable to minimise pain at all.

### Anxiety level — Zung Self-Rating Anxiety Scale (SAS) *vs.* level of pain control

No statistically significant relation between anxiety levels and the level of pain control ( $r = -0.150$ ; NS) as well as respondent's ability to reduce pain ( $r = -0.126$ ; NS) were found.

Anxiety was observed only in 3% ( $n = 2$ ) patients and one of these respondents presented moderate anxiety whereas for the other one (1.5%) it reached a very high level.

### Disease acceptance level — Acceptance of Illness Scale (AIS) *vs.* pain control level and ability to reduce it

The level of pain control (Fig. 1) correlated with the degree of acceptance of disease and this relation was statistically significant ( $r = 0.283$ ;  $p = 0.021$ ). No relationship between patient's skill for reducing pain and acceptance of

illness ( $r = 0.217$ ; NS) was reported. In our study 9.1% ( $n = 6$ ) of adolescents didn't accept their disease, 54.5% ( $n = 36$ ) presented moderate adjustment, and 36.4% ( $n = 24$ ) of patients accepted their condition well.

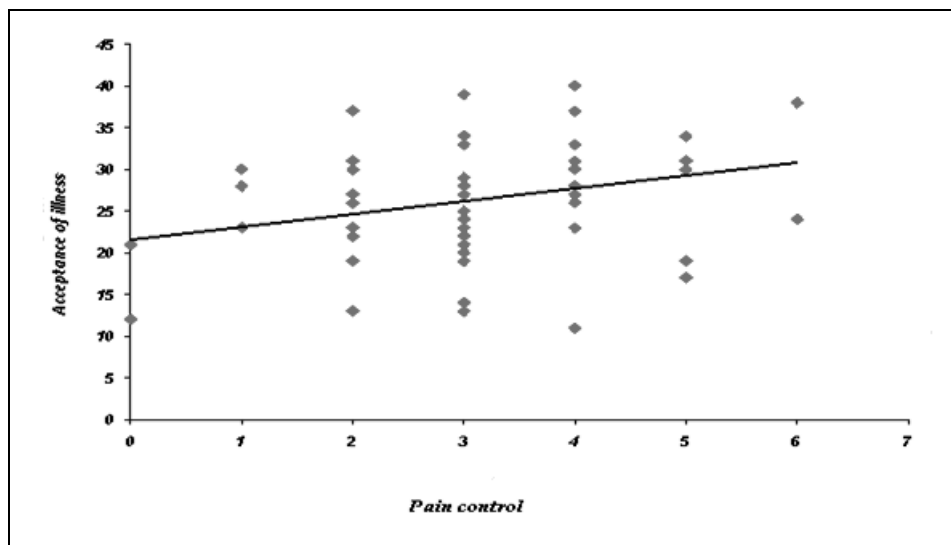


Fig. 1. Correlation between the level of acceptance of the disease and the ability to control pain

### Quality of Life

#### — WHOQOL-BREF *vs.* strategies of coping with pain

A weak negative correlation ( $r = -0.373$ ;  $p = 0.002$ ) was found between the physical domain of quality of life and the level of catastrophizing as well as the level of catastrophizing and searching for hope ( $r = -0.321$ ;  $p = 0.009$ ). Additionally, quality of life in the psychological domain correlated positively with the level of pain control ( $r = 0.249$ ;  $p = 0.044$ ), however this relation was also weak (Tab. 1).

Respondents received highest scores when evaluating their quality of life in the environmental domain ( $\bar{x} = 15.5$ ;  $SD = 1.9$ ; NS) whereas the lowest scores were recorded for the psychological function ( $\bar{x} = 13.8$ ;  $SD = 2.2$ ; NS).

When asked to assess their quality of life and health, adolescents rated their satisfaction with life ( $\bar{x} = 3.77$ ;  $SD = 0.87$ ;  $p < 0.05$ ) higher than health ( $\bar{x} = 2.92$ ;  $SD = 1.13$ ;  $p < 0.05$ ) (Tab. 2).

Table 1

Correlation of ways of dealing with pain and quality of life

	Physical area		Psychological area		Social relations		Environment	
	r	p	r	p	r	p	r	p
Distraction	-0.154	0.217	0.048	0.704	0.038	0.765	-0.134	0.284
Reevaluation of pain experience	-0.156	0.210	0.000	1.000	0.082	0.513	-0.074	0.556
Catastrophic thinking	<b>-0.373</b>	<b>0.002*</b>	<b>-0.197</b>	<b>0.112</b>	<b>-0.239</b>	<b>0.053</b>	<b>-0.105</b>	<b>0.403</b>
Ignoring sensations	0.161	0.198	0.095	0.446	-0.005	0.967	0.132	0.291
Praying / deep hope	-0.200	0.108	0.060	0.630	-0.198	0.111	0.054	0.669
Declaring handling the situation	0.094	0.451	0.165	0.185	0.035	0.782	0.100	0.425
Increased behavioral activity	0.029	0.818	0.129	0.302	0.068	0.589	0.012	0.925
Pain control	<b>0.124</b>	<b>0.322</b>	<b>0.249</b>	<b>0.044*</b>	<b>-0.088</b>	<b>0.481</b>	<b>-0.126</b>	<b>0.315</b>
Ability to reduce pain	0.126	0.315	0.152	0.223	0.041	0.746	-0.063	0.616
Cognitive coping	0.056	0.65	0.115	0.359	0.062	0.621	0.076	0.544
Distraction and taking alternative actions	-0.062	0.622	0.101	0.418	0.048	0.700	-0.062	0.622
Catastrophic thinking and looking for hope	<b>-0.321</b>	<b>0.009*</b>	<b>-0.063</b>	<b>0.616</b>	<b>-0.234</b>	<b>0.059</b>	<b>-0.019</b>	<b>0.877</b>

Table 2

Assessment of the degree of satisfaction with life and health of the respondents on the basis of a questionnaire WHOQOL-BREF

	Mean value	Standard deviation	Minimum value	Maximum value	Amount of valid	Statistics Z of test of normality of distribution
Satisfaction with life	3.77	0.87	1	5	66	2.311
Satisfaction with health	2.92	1.13	1	5	66	1.402

### Respondent's age *vs.* coping strategies and methods for pain control, the degree of illness acceptance, anxiety level, and quality of life

A weak negative correlation ( $r = -0.258$ ;  $p = 0.036$ ) was found between respondent's age and the level of "*praying*" as a method of coping with pain.

Moreover, the degree of pain control correlated negatively with the age of adolescents ( $r = -0.460$ ;  $p = 0.000$ ) (Fig. 2).

No significant relation was observed between respondent's age and the degree of acceptance of illness and anxiety level. Patient's age showed a weak negative correlation with the psychological domain of quality of life ( $r = -0.310$ ;  $p = 0.011$ ).

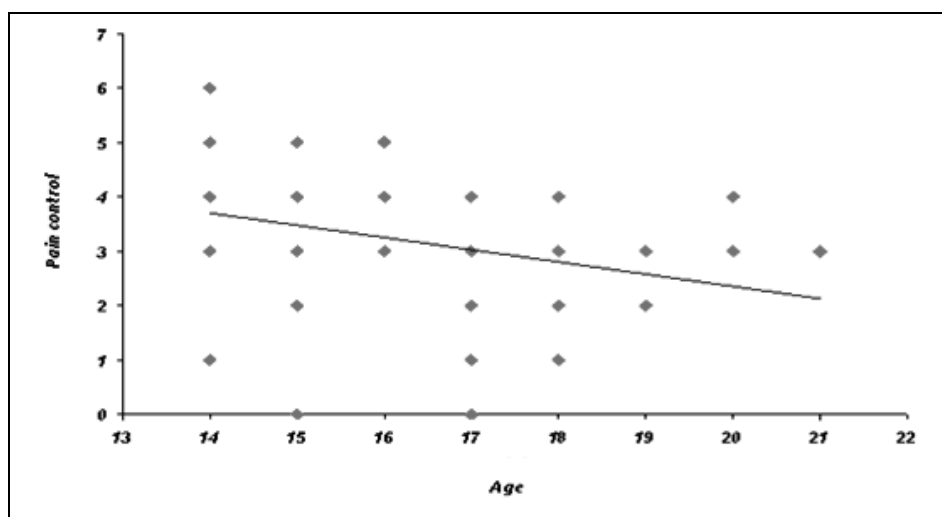


Fig. 2. Correlation between the level of pain control and the age of the respondents

### Relationships between disease duration and adapted strategies of coping with pain, acceptance of illness, and quality of life

We found a statistically significant relation between shorter duration of disease ( $< 2$  years) and stronger use of "*diverting attention*" strategy as a method of coping with pain ( $\bar{x} = 16.92$ ;  $SD = 7.40$  *vs.*  $\bar{x} = 12.43$ ;  $SD = 6.86$ ;  $p = 0.014$ ).

It was also proven that adolescents suffering from their disease for a period shorter than 2 years applied the strategy of reinterpreting pain sensations when managing their pain ( $\bar{x} = 10.69$ ;  $SD = 6.34$  *vs.*  $\bar{x} = 6.50$ ;  $SD = 5.83$ ;  $p = 0.007$ ).

These respondents used two other strategies, diverting attention and increasing activity level, more frequently when compared with young patients being ill for longer time ( $\bar{x} = 32.58$ ;  $SD = 13.96$  *vs.*  $\bar{x} = 24.73$ ;  $SD = 14.22$ ;  $p = 0.028$ ). (Tab. 3).

No relation was found between disease duration and the degree of acceptance of disease and quality of life declared by our respondents.

Table 3

Relationship between duration of disease and the strategies used to cope with pain

	Under 2 years		Over 2 years		Results of the test t/U	Degrees of freedom	Significance of the test t/U
	Mean value	SD	Mean value	SD			
Distraction	16.92	7.40	12.43	6.86	2.53	64	0.014*
Reevaluation of pain experience	10.69	6.34	6.50	5.83	2.77	64	0.007*
Catastrophic thinking	10.75	6.72	9.13	7.53	0.92	64	0.360
Ignoring sensations	15.86	6.92	14.20	9.05	0.82	53.59	0.413
Praying / deep hope	20.17	7.82	18.13	9.91	0.93	64	0.355
Declaring handling the situation	20.47	6.96	18.90	7.97	0.86	64	0.395
Increased behavioral activity	15.67	8.17	12.30	9.00	1.59	64	0.116
Pain control	3.19	1.14	3.07	1.31	491	–	0.511
Ability to reduce pain	2.81	1.12	2.87	1.11	532.5	–	0.917
Cognitive coping	47.03	15.70	39.60	18.48	1.77	64	0.082
Distraction and taking alternative actions	32.58	13.96	24.73	14.22	2.26	64	0.028*
Catastrophic thinking and looking for hope	30.92	12.06	27.27	15.51	1.08	64	0.286

## DISCUSSION

Malignant disease and its consequences have been studied extensively, however we still have no answers to many problems experienced by patients. Pain and its effects belong to these problems. Wide range of research projects has revealed



that the majority of paediatric cancer patients suffer from pain [3, 4, 11, 12]. Not only should pain be prevented or treated due to numerous moral, ethical, humanitarian, and physiological aspects, but special attention should be paid to recognition and evaluation of symptoms induced by pain or coexisting with it [13–15], which determine patient's functioning.

The need for deeper knowledge about the influence of pain on patient's emotional status, adaptation to disease, and quality of life of adolescents suffering from malignant diseases motivated us to conduct this study. Teenage cancer patients should be recognised as a subgroup of patients receiving oncologic treatment with needs requiring targeted interest and interventions, also because the management of malignant diseases among adolescents has not been organised within one structure including diagnostic procedures and medical therapy and care.

All our respondents experienced pain, however they didn't need continuous or regular administration of pain relief medications. This doesn't mean that patients with hematopoietic malignancies require no pharmacological analgesia at different stages of their disease. It should be noticed that our study group didn't include patients in severe condition, undergoing chemotherapy, and patients who developed complications directly responsible for inducing pain. Pain intensity measured with two different scales i.e. VAS and NRS was lower than 5. The majority of adolescents had partial control over their pain sensations and were able to change them to some extent. The extraction of correlations between variables showed that higher levels of pain control determined higher degree of acceptance of illness. However, the lack of sufficient evidence in this field makes it difficult to compare our findings with other studies.

The analysis of results obtained in this study indicated that only a small group of respondents manifested anxiety. According to theoretical assumptions and the conclusions presented in other publications, every paediatric patient suffering from acute, recurrent or chronic pain experiences anxiety [16] and in some of these patients anxiety levels are high [12]. Studies by Cepuch *et al.* [17] using the same measuring tools and Cepuch *et al.* [18] using HADS also showed low percentage of adolescents experiencing anxiety. This discrepancy between results presented by different authors may have numerous causes, e.g. different tools and differences in age profile of the study groups. Additionally, other variables should be taken into consideration since they may affect final results. It is possible that disease duration was one of factors changing outcomes because early diagnosis induces greater anxiety whereas longer period of chronic disease is often related to depression. Li *et al.* [19] also support this theory. They showed that paediatric cancer patients manifested significant anxiety during the preliminary stage of hospitalisation and more than half of this group presented depressive symptoms during their hospital stay. Also, the possibility that patients from this age group mask their symptoms can't

be ruled out and indirect measuring tools used for evaluation of anxiety (e.g. HADS) may not be sufficient to verify emotional status of a teenage patient.

The assessment of patient's functioning as well as his/her adaptation to disease is very important, especially in malignant illnesses. The level of pain and anxiety experienced by the patient are only two of many factors determining quality of life [3]. In our study, adolescents received the highest scores in the environmental domain, which is consistent with other publications [17]. Respondents assessed their psychological functioning as poor. Additionally, it was shown that quality of life in the psychological domain decreases with patient's age. At the same time, higher levels of pain control correlated with better quality of life in the psychological domain. These findings confirm that psychological evaluation of a patient should be performed on regular basis, and research in this field continued, especially for this range of emotional status. Next to pain, anxiety and disorders of depressive character may be treated as the major determinants in the struggle against disease. Summarising, adolescents with leukaemias and lymphomas evaluated their quality of life as good, which was confirmed by findings from our other studies [3, 4]. Cepuch and Wordliczek [20] showed that young patients with malignant diseases were satisfied with their lives not only in their current evaluation but also in predictable future.

A review of literature indicated a direct correlation between quality of life and experienced pain [4]. Jörngården *et al.* [21] studied quality of life of adolescent cancer patients and concluded that young patients were well adapted to their trauma. Moreover, when higher levels of stress were observed which lasted for longer period of time teenagers were more resistant to it. However, Rajeev *et al.* [6] noticed a very important fact in their study that in difficult situations young patients applied the same coping strategies as their parents.

Ogińska-Bulik and Izydorczyk [22] showed that paediatric patients with leukaemia preferred active strategies for coping with stress more often than their healthy peers. Numerous studies confirmed [23, 24] that active coping methods promote recovery and cancer patients present better adaptation to their disease and experience less intense symptoms of anxiety and depression. Effective strategies for coping with pain sensations are a form of active resistance to hematopoietic cancers. Heszen and Sęk [25] emphasize the fact that the sense of control over health, including pain, and life is an important factor for the process of coping and adaptation to disease. Our findings indicate that the level of coping with pain is related to the degree of acceptance of illness, better outcomes in the psychological domain of quality of life, older age, and shorter period of disease duration. However, this study should be interpreted as a pilot project and its results as preliminary outcomes requiring further research.

## CONCLUSIONS

1. Identification of present problems and needs of adolescents diagnosed with leukaemia or lymphoma may affect the process of reinforcing, developing, and looking for new subjective and situational resources, which determine effective coping with pain and ability to control it.

2. Discrepant outcomes of studies on the prevalence of anxiety among adolescents with cancer suggest these studies should reach deeper. It can't be ruled out that patients tend to mask disturbing symptoms or present repressive coping, which may bias study results.

3. Teenage patients with malignant diseases are well adapted to their disease and their ability to control pain and reduce it is the factor, which significantly affects the process of adaptation.

## CONFLICT OF INTEREST STATEMENT

None declared.

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